
What Can New York Do About Prescription Drug Costs and Access?

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Costs and other barriers prevent access to needed medications

- 45% of New Yorkers avoided care due to cost and several of those actions involved prescriptions: cutting pills in half, skipping dosages, never filling a prescription at all
- 1 in 4 people who need insulin ration it because they can't afford taking as much as they need
- Among registered voters age 50-plus who report not filling at least one prescription in the past two years (24%), six in ten (60%) cite cost as a factor

Sources: Altarum Healthcare Value Hub and CSSNY, "New Yorkers Struggle to Afford High Healthcare Costs; Support a Range of Government Solutions Across Party Lines," March 2019, <https://www.slideshare.net/CSSNYorg/hub-altarum-data-brief-no-37-new-york-healthcare-affordability-134957974>; Herkert et al., "Cost-Related Insulin Underuse Among Patients with Diabetes," January 2019, JAMA Intern. Med., 179(1): 112-114, doi:10.1001/jamainternmed.2018.5008; and AARP, "2019 Prescription Drug Survey – New York Registered Voters Age 50+, https://www.aarp.org/content/dam/aarp/research/surveys_statistics/health/2019/new-york-prescription-drug-survey.doi.10.26419-2Fres.00361.001.pdf



Gone but not forgotten/passed but not done

- Prohibiting drug formulary changes during a contract year: A2969a/S2849a
 - When you enroll in a health plan you are locked in – but the benefits are not locked in, including your drug coverage
 - Passed Assembly and Senate, vetoed by Gov. Cuomo
- A8533b/S6492b – passed but different:
 - Would create a drug assistance demonstration program modelled after an existing program for people with HIV or AIDS to provide access to “life sustaining maintenance prescriptions,” report was due in June 2019

Regulating pharmacy benefit managers

- PBMs process drug claims, manage formularies, set reimbursement rates and pay pharmacies, and negotiate with manufacturers
- Vertical integration and market consolidation
 - 3 PBMs control 80-85% of the market
 - CVS is a PBM and a pharmacy chain
- Actions that generate more revenue for PBMs keep people from accessing medications they need and may raise prices for all of us
 - Spread pricing: Pay a pharmacy \$10 for filling a prescription, tell the plan you work for that it cost \$100, earn \$90
 - Making it hard for patients if they don't use the PBM's retail locations or mail order service



All of this happens in a black box – this what many people think is happening, but there is no regulation or public disclosure requirements that let us know for sure.

Current proposal: register/license pharmacy benefit managers

- PBM licensing legislation has passed before but been vetoed (A2836a/S6531)
- Another version was included in Part J of the Executive Budget:
 - Registration until 2023, then licensing
 - Reporting requirements include information on reimbursements, incentive agreements (for example with manufacturers), rebates, and other financial agreements
 - Minimum licensing standards could include prohibitions on anti-competitive practices, spread pricing, and requirements for pharmacies in-excess of or inconsistent with state requirements
 - Fine for violations and possibility of having license revoked



A T1International Chapter

New York #insulin4all

**Legislative Priorities
For 2021
Budget Negotiation**

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S.6492 (Rivera) / A.8533 (Joyner) 2019-2020

S.6492a - Established a \$100 copay price cap on insulin(s), applies to private insurance plans regulated by NYS, *excludes* the uninsured, Medicaid and Medicare insured. Passed as part of the 2020 budget negotiation.

S.6492b - Emergency Refills (Kevin's Law) and a Drug Assistance Demonstration Program



"How can I afford to live with diabetes?"



OPINION

A29

NY needs to boost access to insulin

Bills won't outright fix persistent problem, but they would provide relief to diabetics

BY MELISSA PASSARELLI

For New Yorkers with diabetes like me, obstacles to obtaining insulin have created a health crisis that we take as seriously as the spread of the coronavirus. Now, more than ever, we need Gov. Andrew M. Cuomo and state lawmakers to ensure we survive by making insulin more affordable and accessible.

I have type 1 diabetes and if I stopped infusing or injecting insulin, I would die within a few days. Yet because of the high price of insulin, even though I have health insurance, I've had to ration the medication by taking less than is necessary for healthy blood sugar levels, risking early complications and death from high blood sugar. I'm not alone: According to studies by Yale University and T1International, 1 in 4 diabetics have skipped on insulin because they can't afford it.

Addressing this problem was urgent before the COVID-19 pandemic but now it is imperative. People with diabetes — es-

pecially those who can't afford the necessary medications — have a higher risk of dying from the virus. Even without infection, lacking access to insulin can cause people with diabetes to have dangerously high blood sugars, resulting in more visits to and strain on New York's overburdened health care system.

Additionally, New Yorkers with diabetes are among the estimated 9 million Americans who've lost their employer-sponsored health insurance due to the pandemic. Now they will be forced to pay full price for insulin, or ration their supply.

New York State recently made insulin a bit more affordable by enacting a price cap of \$100 per month for copays for New Yorkers with private insurance. That will help me, as I now pay about \$500 per month for insulin even with insurance. But it won't help uninsured and low-income New Yorkers, nor does it address other barriers to obtaining insulin. According to an analysis by the online site Data for Insulin, it will only



Allie Marotta, who grew up in Patchogue and Bayport and has type 1 diabetes, joins protest in November in Manhattan to call for affordable insulin for those who need it and can't afford it.

apply to about 27% of insulin-using New Yorkers.

It's critically important for the State Legislature to work with Cuomo to address this life-threatening problem. They can start by passing and enacting a new insulin bill. This bill mandates the state to create a drug assistance "demonstration" program, which would study how to provide insulin to people who are uninsured or ineligible for Medicaid, as well as other low-

come, underinsured diabetics. The bill also would allow pharmacists to dispense emergency prescriptions for insulin and other noncontrolled, life-sustaining drugs.

Right now, people in New York who run out of insulin can't get refills without a new prescription from their doctors. If that happens on a time when we can't reach our doctors who are busy dealing with the pandemic, we are faced with a daunting choice: Either we go

to very crowded emergency rooms — and risk COVID-19 infections — or we don't take insulin and risk death.

If pharmacists were able provide emergency refills, people with diabetes wouldn't be forced to make this impossible decision.

Another bill recently introduced by Sen. Gustavo Rivera would lower the maximum copays from \$100 per month per type of insulin to \$50 per month, making insulin more affordable and accessible to people who depend on it.

These bills won't permanently solve the greater insulin affordability and accessibility crisis. But at a time when we must do everything we can to manage the capacity of our health care system, they would prevent the unnecessary utilization of emergency care, and they could save lives.

Melissa Passarelli of Dix Hills is a member of New York T1International, a chapter of T1International, which advocates for people with type 1 diabetes around the world.



Covid-19 Vaccinations for People with Diabetes

Beginning February 15th, 2021, people with **Type 1 Diabetes** or **Type 2 Diabetes** will be eligible to receive Covid vaccinations in NY State as part of 1b.

This is an update to CDC guidelines which prioritized Type 2 Diabetes, but not Type 1, for early vaccination. We cosigned a letter along with research physicians at Vanderbilt University and other patient advocates that was sent to the CDC by our parent organization, T1International.

The real question is... why not **ALL** diabetics??!! Or at least those who depend on insulin and can supply an insulin rx.

A.3007 / S.2507 (Budget)

Part P - Updates the scope of practice for pharmacists allowing them to *adjust* or *renew* an existing prescription for continued management of a chronic health condition; allows a pharmacist to be the referring healthcare professional for diabetes and asthma management

Insulin Specific Bills we like in 2021-2022

S.1413 (Rivera) / A.2383 (Niou) - Lowers the copay price cap to \$30

S.4000 (Rivera) - Workgroup negotiated by the governor to replace the Drug Assistance Demonstration Program. We won the demand to have one insulin dependent person included in the workgroup.

A.194 (Gottfried) - Establishes an emergency insulin program and corresponding emergency insulin program trust fund

S.3048 (Rivera) - Enacts the “New York affordable drug manufacturing act of 2021”

Other Stuff We Think Is Important

Mutual Aid - Mutual Aid Diabetes, <https://mutualaiddiabetes.com/>

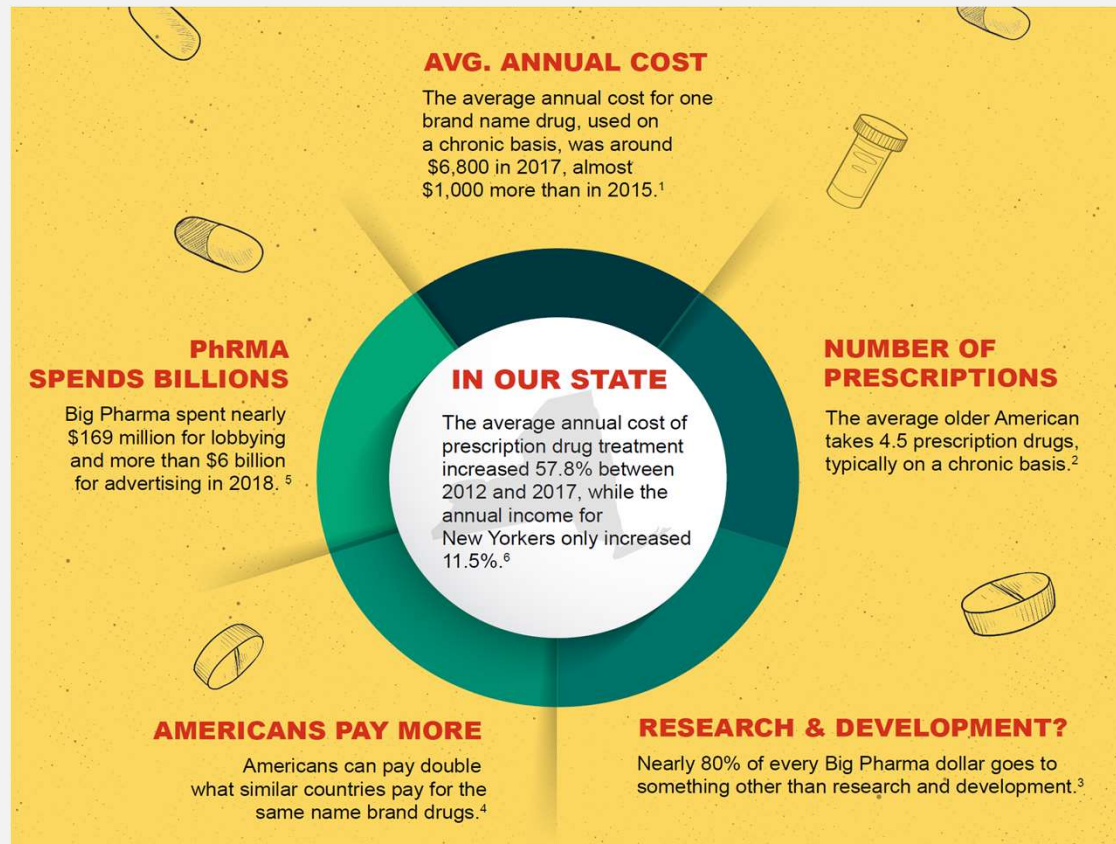
340B - Save New York's Safety Net, <https://www.savenysafetynet.com/>

Medical Debt Protection Act - We the Patients of CSSNY, <https://wethepatientsny.org/insulin4alls-melissa-passarelli-8000-out-of-pocket-costs-rationing-depletion-of-savings-the-cost-of-affording-insulin/>

Revenue Raising - Invest in Our New York, <https://www.investinourny.org/>

New York Health Act - Campaign for New York Health, <https://www.nyhcampaign.org/>

PRICE GOUGING



Drug Accountability Board

- New DFS Office of Pharmacy Benefits can investigate prescription drug price increases
- Consults with the Drug Accountability Board
- Consumers can submit complaints on DFS website

Report A Drug Price Spike

Use the **DFS Portal** to report a dramatic increase in the cost of a drug or pharmacy benefit that you use. You can also check the status of a complaint, or add information to an existing complaint. Be aware that we may share a copy of your complaint with the company or individual you are complaining about.

To get started please **visit our secure Portal**:



DFS Portal

Rx Importation

DECEMBER 18, 2019 | Albany, NY

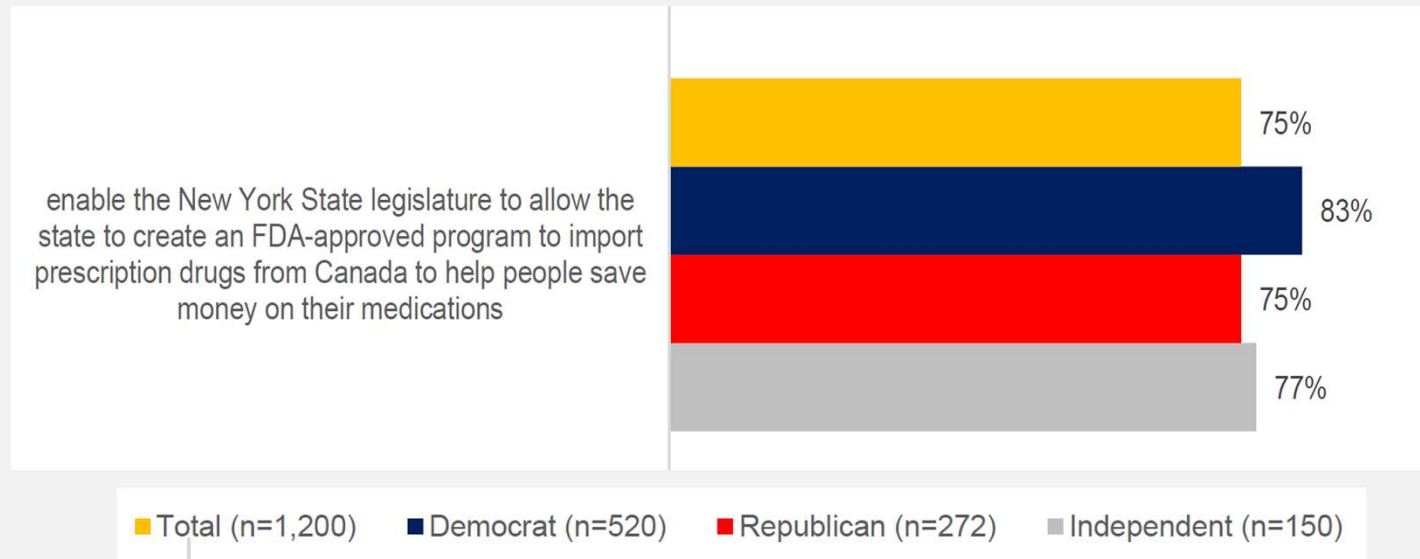
Governor Cuomo Unveils 6th Proposal of 2020 State of the State: Lowering Prescription Drug Prices for All New Yorkers Through Comprehensive Three-Part Plan

2020 STATE OF THE STATE

HEALTH

Rx Importation

Percent of voters age 50+ indicating support:



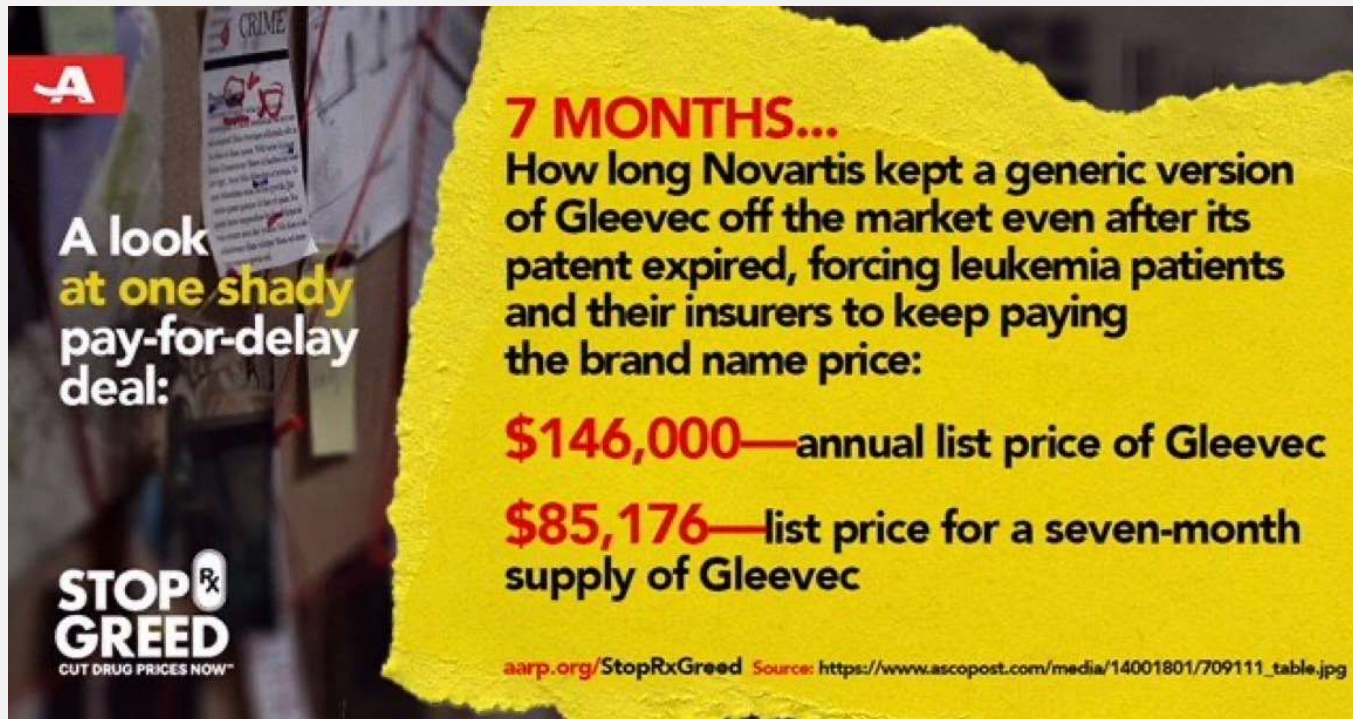
Rx Importation

**Bring safe Rx importation
to New York!**

Call today and urge Governor Cuomo to launch his
prescription drug importation commission.

Call toll free: **(844) 254-6882**

Pay-for-Delay



A

A look at one shady pay-for-delay deal:

STOP Rx GREED
CUT DRUG PRICES NOW™

7 MONTHS...
How long Novartis kept a generic version of Gleevec off the market even after its patent expired, forcing leukemia patients and their insurers to keep paying the brand name price:

\$146,000—annual list price of Gleevec

\$85,176—list price for a seven-month supply of Gleevec

aarp.org/StopRxGreed Source: https://www.ascopost.com/media/14001801/709111_table.jpg

Pay-for-Delay

S.4370 (Biaggi) – bans pay-to-delay agreements

Based on successful law passed in California

California Ban on ‘Pay to Delay’ Pharma Deals Survives First Challenge